

Governor's Conference Testimony – December 8, 2004

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CAREGIVERS

I am pleased to be presenting this testimony addressing the need to expand and maximize the flexibility of the National Family Caregiver Support Program based on my 18 years of experience at Central Illinois Agency on Aging with 8 of those as Executive Director and 8 years with Illinois Taskforce on Grandparents Raising Grandchildren, currently as co-chair. Due to my length of experience, I have seen before, during and after the implementation of the National Family Caregiver Support Program.

- **Expand eligibility to include all caregivers age 60 or older no matter the age of the care recipient.**

An older caregiver not only has the challenges of being a caregiver but also any of those that may be related to their age. Current age eligibility for Title III-E Caregiver services leaves out the caregiver that is 60 years or older who is caring for an individual, typically an adult child, between the ages of 18 and 60 years. This especially is significant in the MR/DD arena with that population now living longer. Annette, 72, is a prime example of this. She has her own health issues, yet is a caregiver for her husband, 71, who is an amputee with diabetes, a heart condition and prostate cancer. Her caregiver responsibilities do not end there; she is also the caregiver for two of her sons, 43 and 42, who are both wheelchair-bound due to cerebral palsy and accident related quadriplegia, respectively. When having to be hospitalized for unexpected surgery, Annette was able to receive respite services for her husband only because of eligibility guidelines for Title III-E services.

- **Funding increase to provide a minimum of 2 days respite per month for every caregiver, with the flexibility to use these days cumulatively and in a setting appropriate to the caregivers needs, i.e. skilled-care facility, over night, ADS, or in-home.**

On a national level, a study completed by MetLife Foundation in collaboration with AARP reported that 5% of their caregiver sample used ADS and another 5% used other Respite services. Respite numbers for Illinois show 2688 caregivers received 136,268 units of service in FY03. Six months through FY04 reveal 1581 caregivers received 62,469 units of respite services with some areas also utilizing Title III-B funds. A range of \$400 to \$1500 was allotted per caregiver depending on the Area Agency and funds available and using estimated costs for respite, this would amount from 6.6 to 20 hours per month per

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caregiver. Locally, respite cost vary from \$10 per hour for ADS, \$16.85 per hour for a CNA, \$34-\$40 per hour for LPN/RN, to \$135 per day for nursing home. Granted, these costs are only an average and will fluctuate based on the level of care needed for the care recipient. Caregiving is as much a full-time job as any other. Full-time employees get vacation benefits; why should caregivers be any different?

Jose, 80, is caregiver for his wife, 78, with middle stage Alzheimer's. She is still able to attend ADS with an Alzheimer's specific group. They have one daughter who works full-time as a researcher. Wanting to keep his wife at home, he struggles when his respite allotment for the year is used up and he can not afford to private pay. He is steadily getting more depressed for which he occasionally will consent to counseling. His stress tests are extremely high with his own health being affected.

- **Expand the definition of respite services to increase access to a variety of care options and available service modalities.**

The State of the States in Family Caregiver Support: A 50-State Study completed by Family Caregiver Alliance National Center on Caregiving reported that one program respondent said, "Respite means different things to different people." Some program administrators view respites as a specific service; others view it as an outcome of providing other out-of-home or in-home services, such as personal care or homemaker/chore services.

Respite services should be viewed as stress reduction services, which may include therapeutic massage, yoga, and Tai Chi for the caregiver. Another avenue should also consider recreational activities such as those in conjunction with park districts.

A specific barrier in respite services for caregivers is the limitation on being able to pay family, friends, or neighbors when strangers are unable to provide care in or out of the home. This is quite common for care recipients with dementia. Dorey, 72, doesn't drive. She cares for her husband, 76, in a rural area with no accessible ADS. He has a history of a stroke that has left him wheel-chair bound and unable to verbally communicate. She has a history of heart attack and ongoing heart condition. They are isolated and homebound. She receives counseling via the phone but doesn't want strangers in their home. They have a niece who is a CNA who would be willing to work for lower wages but must receive some wages as she is a single working mother. Dorey is unable to pay privately even with the reduced cost.

- **Promote a national cooperative educational effort along with the Department of Labor to work with and encourage employers to establish worksite support groups and individual counseling, to increase employer awareness of working caregiver needs and benefits to employers.**
- **Establishment of a tax credit for employers who provide caregivers programs for their employees.**
- **Work with educational institutions (i.e. social work, counseling departments) for the establishment of "warm lines" and home-based counseling.**
- **Work with and educate faith communities to establish on-site support groups and telephone support programs.**

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Caregivers have a stressful job just being a caregiver but that stress is exacerbated when the caregiver is either working or homebound. According to a study by Met Life, more than 50% of the nation's caregivers work outside the home in either a part-time or full-time capacity. More than six in ten of these working caregivers report their caregiving responsibilities have affected their work. Steven, 60, a working caregiver, cares for his aunt, 91, who has no other family. She was in a nursing home but was removed when the family could no longer pay the bill. Steven is very stressed due to varied and long hours at work with no time available to attend support groups. So far his employer has understood about his care situation. But Steven worries that as his aunt becomes more disabled, more care will be required of him that will force him to miss work.

- **Establishment of a tax credit for caregivers, similar to that for child care.**
- **Expand definition of Supplemental Services to allow for individuals whose supplies are not covered by private insurance, Medicaid, or Medicare, an allocation up to \$300 per month for partial reimbursement of out-of-pocket expenses for such items as Depends, bed pads, personal toiletries, nutrition supplements and equipment.**

A random survey conducted by AoA with results included in AoA's 2003 Annual Report reported that 52% of respondents said they needed a stipend, tax break or other financial help. Caregivers are not only giving of themselves emotionally but in many cases also financially. A Met Life Study reported a range of \$150-\$437 per month in basic caregiving costs.

GRANDPARENTS RAISING GRANDCHILDREN

In Illinois, the Taskforce has been active since 1996 and always has been represented by both aging and child welfare interests. Moreover, the Illinois Department on Aging has been the lead entity in convening a broad based coalition of state and local agencies and organizations from these sectors to address policy, education, and resources to meet the needs of this growing segment of the population, with considerable outcomes on behalf of Illinois' relative caregivers and their children. The National Family Caregiver Support Program has provided a mechanism for coordinating state and federal services and benefits through the cooperation of the Illinois Department on Aging, Area Agencies on Aging, Illinois Department of Human Services, and Illinois Department of Children and Family Services. Similarly, this testimony proposes a lead role for the Administration on Aging as an outcome of the 2005 White House Conference on Aging in bringing to fruition the following recommendations.

- **Expand and maximize the flexibility of the National Family Caregiver Support Program (NFCSP).**

Services provided under Title III-E's NFCSP appropriately are to caregivers of all ages, with the exception of grandparents raising grandchildren. However, services funded and provided under the NFCSP through the allowable allocation for grandparents raising grandchildren consistently result in the documentation of need for services among such caregivers who are under the age of 60 years. The majority of III-E services can be provided in ways that address the universal needs of caregivers across the lifespan, and those services provided uniquely for grandparents and other relatives raising children

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more often than not also apply to all such caregivers regardless of age. The Illinois Taskforce and I4A recommend as a WHCOA outcome support for a funding increase for the NFCSP and that the Older Americans Act (OAA) allow for a lifespan approach to the implementation of NFCSP services. The precedent for providing services to an under 60 population is further established through the age 55 eligibility for employment services under Title V of the OAA, which at a minimum establishes a framework for less than age 60 years for services to grandparents. In addition to the age restrictions, there is also a need to explore ways to increase flexibility in the current 25% match requirement for Title III-E and the current restrictions in the definition of respite services which make provision of services prohibitive at the area level and for some caregivers, such as respite restrictions on grandparents who lack formal custody or creative respite options for caregivers in general.

- **Increase the Administration on Aging's ability to take the lead in national direction and funding assistance for State Units on Aging and Area Agencies on Aging to do the education and training, advocacy, program development and coordination needed at the state and local levels.**

Effective implementation of these vital OAA functions, at the federal, state and local level, is critical to the achievement of the intended outcomes of the NFCSP. As an example, at the state level in Illinois, the Department on Aging obtained the support of state level departments and statewide organizations to secure their participation in developing a planned approach to services and policy changes on behalf of grandparent caregivers. Similarly, a national collaboration is needed among a broad network of governmental and social service agencies to provide a package that meets the needs of a broad range of kinship caregivers. Examples of these include the varying approaches and resources needed to establish a network of services for:

- Caregivers of adult children with disabilities through aging and disability service systems
- Grandparents raising grandchildren who qualify for TANF for themselves and are bound by federal time limit and work requirements and increasing "child only" grants for those who need adequate resources just to meet the child's needs
- Expanding subsidized guardianship programs to cover grandparents and other relatives who care for children not involved with the child welfare system
- Allowing for subsidized guardianships the "money to follow the child" when responsibility for care of the children is transferred
- Kinship navigator programs to increase access to services
- Housing supportive of nontraditional families, including caregivers of adult children with disabilities and "grand family homes" for grandparents raising grandchildren
- School enrollment legislation for the benefit of school districts and the children
- Developing medical consent laws and policies requiring public health departments to conduct outreach and education about medical consent
- Training the judicial system, lawyers and judges and partnering with organizations such as the American Bar Association and legal services programs
- Obtaining a tax credit for caregivers
- Accessing health insurance and medical benefits, legal status, mental health, respite and education
- Flexibility in the use of NFCSP supplemental funds